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About Controlling cancer pain

This booklet is about cancer pain. It describes the wide variety of medical and complementary treatments available for controlling your pain.

About 3 in 10 (30%) people will have some pain when they are first diagnosed with cancer, and about 7 in 10 (70%) people have pain if their cancer is advanced (has come back or spread). If you have pain, it’s important to always tell the doctors and nurses looking after you so they can treat it. As pain is different for each of us, it needs to be treated on an individual basis. Even people with the same type of cancer have very different experiences.

The amount of pain you have is not related to how severe your cancer is. Having pain doesn’t necessarily mean that the cancer is advanced or more serious. Pain doesn’t automatically get worse as the cancer develops.

We hope that this booklet answers some of the questions you may have about cancer pain and its treatment, and helps you deal with some of the feelings you may have. You may find that not all of the sections in this booklet are relevant for you.

It’s fine to just read the sections that you find most helpful. We can’t advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.
If you’d like to discuss this information, call the Macmillan Support Line free on 0808 808 00 00, Monday–Friday, 9am–8pm. If you’re hard of hearing, you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively visit macmillan.org.uk

Turn to pages 64–81 for some useful addresses, helpful books and websites, and page 82 to write down questions for your doctor or nurse.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.
What is pain?

Pain is an uncomfortable, unpleasant physical sensation as well as an emotional experience that occurs when tissues in the body are damaged.

The nervous system is made up of your brain, spinal cord and a network of nerves that run throughout your body. The brain is the control centre for your body.

There are several steps involved in feeling and reacting to pain:

• Certain nerves throughout the body have endings known as **pain receptors**. These can be activated by pressure from a tumour or by chemicals released from damaged tissue.

• The pain receptors then send messages along the nerves first to your spinal cord and then to your brain. When painful messages reach your brain, you feel pain.

• The brain responds to pain by sending other messages back along the nerves to direct your reaction. For example, if you feel pain when you move your arm, you may react by keeping it still.

The brain can change the way you feel pain. For example, parts of the brain that control our emotions can increase or decrease the sensation of pain. So if you’re anxious you may feel more pain, and if you’re relaxed you may feel less pain.

Sometimes the nerves carrying messages to and from the brain become ‘sensitised’ or ‘wound up’. This means that you continue to feel pain even when what was causing the pain has been treated.
Causes of pain

Physical causes

People with cancer may have pain for a number of reasons. For example, the cancer may press on the tissues around it or on a nerve.

Cancer treatments can also damage or injure tissues. Surgery causes pain, as tissues are cut or damaged. Radiotherapy and chemotherapy treatments can also damage tissues. For example, chemotherapy can damage the soft tissues in the mouth, causing soreness. Radiotherapy treatment can damage the skin in the area being treated. The pain usually goes away once the treatments are completed and the damaged tissues have healed. Sometimes radiotherapy and chemotherapy treatments can damage nerves and lead to a type of pain known as neuropathic pain (see page 8).

Pain isn’t always due to cancer. A person may have other health conditions, such as arthritis, that cause pain.

If you develop a new ache or pain, you may understandably worry that this is a sign that the cancer has come back, is getting worse or has spread, but this is not necessarily the case.

It’s always best to get any new pain checked out by your doctor so you can get the right treatment.
Emotions and pain

Emotions such as fear, anxiety, depression and tiredness can make your pain feel and seem worse. This doesn’t mean that cancer pain is ‘all in the mind’. Symptoms of many physical illnesses, including asthma, heart disease and stomach ulcers, can be made worse by emotional upset. In all of these conditions, as with pain from cancer, it’s important to treat the emotional as well as the physical causes of the problem.

Social effects on pain

Sometimes pain can be made worse by social- or work-related pressures that cause you stress. For example, not being able to see friends or not being able to work can influence pain levels.
Pain terms

There are a number of different terms that you might hear your doctors or nurses use to describe pain:

**Acute pain**

Acute pain is short term. It’s often caused by cancer treatments such as surgery.

**Chronic pain**

Chronic pain persists over a longer period of time. With cancer, it’s usually caused by the cancer itself, but it can sometimes be caused by cancer treatments.

**Neuropathic (nerve) pain**

This is a term that describes pain caused by nerve damage. This may be due to tumour growth or cancer treatments. It can also be caused by nerves becoming ‘sensitised’ or ‘wound up’ (see page 5). Neuropathic pain is a type of pain that comes and goes; you may describe it using words such as burning, stabbing, shooting, tingling, radiating or spreading. There are specific medicines that can help treat neuropathic pain (see page 36).

**Breakthrough pain**

This is pain that occurs when pain is generally being well controlled with painkillers. It may be brought on quite suddenly by an activity, such as walking or coughing, or it may happen when the effect of the regular painkiller wears off.
Total pain

Total pain is a term doctors and nurses use to describe all the different parts of a person’s pain. This includes how the pain affects and can be affected by our emotions, our behaviours, our spiritual beliefs and our social activities.

Whether you have acute, chronic, neuropathic and/or breakthrough pain, these pains can almost always be controlled with the right treatments.
Describing pain

Describing your pain as fully as you can will help your doctors and nurses work out the best way of treating it. Here are some questions that will help you to describe your pain:

• **Where is the pain?**
  Is it in one part of your body or in more than one place?

You can use diagrams like the one on the right to mark where your pain is. If you have more than one pain you may want to label them (eg A, B, C).

We have included the same diagrams on the back page of the pain diary (see the centre of this booklet).

• **What is the pain like?**
  For example, you may use words such as aching, tender, sharp, hot, burning, nagging, intense, stabbing, tingling, dull or throbbing to describe your pain.

  For more examples of words you can use to describe your pain, look on the back page of the pain diary that is located at the centre of this booklet.
• **How bad is your pain?**
  If you measured it on a scale of 0 to 10, how would you rate it (where 0=no pain and 10=the worst pain you’ve ever had)?

  ![Pain Scale](scale.png)

• **Is the pain there all the time?**
  Does it come and go? Does it go if you sit still or get worse when you move? Is it worse at night? Does it keep you awake or wake you up?

• **Does anything make the pain better or worse?**
  Do you feel better or worse standing, sitting or lying down? Does a heat pad or ice pack help? Is it relieved by painkillers such as paracetamol? Do the painkillers stop the pain or just reduce it, and for how long? Can you distract yourself with activities such as reading, listening to music or watching TV?

• **How does the pain affect your daily life?**
  Does it stop you from bending or stretching as usual? Does it stop you from sitting for very long – for example, can you sit long enough to eat a meal? Does the pain stop you from concentrating or affect your sleep? Does it stop you from walking for short or long distances?

Don’t feel that you’re being a nuisance or making a fuss by talking about your pain. Your answers to these questions will help your doctor or nurse plan the best treatments for you.
Controlling cancer pain
Keeping a pain diary

It can help to keep a record of your pain. List how bad it is at different times of the day and note anything that makes it better or worse. This information can help you discuss your pain with the doctors or nurses looking after you. Some hospitals will give you a pain chart.

You can also use the pull-out pain diary in the centre of this booklet. You might want to photocopy it before you fill it in; then you can use it as often as you need to. You may find it helpful to photocopy the back page of the diary as well, as it contains a diagram to mark where the pain is and a list of words that may help you describe your pain.

Managing pain

How your pain is managed will depend on a number of factors, such as the cause of the pain and how bad it is for you. Painkillers are often used, but you may also have treatments such as radiotherapy or chemotherapy (see page 38). Other ways to control your pain include TENS (transcutaneous electrical nerve stimulation), nerve blocks, acupuncture and relaxation therapies (see page 41).

Your pain management team

A number of healthcare professionals may be involved in managing your pain. These healthcare professionals specialise in different aspects of pain management and work closely together. They include your GP and your cancer doctors at the hospital. The following teams or people may also be involved:
**Pain teams**
Many hospitals have pain teams that have specialist doctors – usually anaesthetists – and nurses who advise on all aspects of pain control. Some teams also have a psychologist. The doctors and nurses who work in pain teams are skilled in using all the methods of pain control discussed in this booklet, but they specialise in the use of nerve blocks (see page 43).

Your GP may refer you to a pain team or you may be referred by your palliative care team, particularly if your pain is troublesome and you need a nerve block.

**Physiotherapists and occupational therapists**
A physiotherapist may be able to show you different ways of moving yourself so that your pain isn’t made worse by movement (see page 44). They can also arrange for you to have a wheelchair if that will help you move around more easily.

An occupational therapist may be able to supply you with equipment, such as special cushions or mattresses, to make you more comfortable when you are sitting up or lying down. They can also assess whether you need aids for daily living, such as handrails and ramps for your home so that you can get around more easily.

Your GP, nurse or hospital doctor can refer you to a physiotherapist or occupational therapist.

**Counsellors and psychologists**
Some people may find it helpful to see a counsellor or psychologist about their pain. They can help you develop skills to cope with the pain and manage any worries or concerns that may be making your pain worse (see page 47).
Palliative care teams
Palliative care teams can be based in a hospital or the community. They include doctors and palliative care nurses and may also include physiotherapists, occupational therapists and counsellors.

Hospital teams only work in the hospital. They can help you with your pain control if you’re attending an outpatient clinic or if you’re an inpatient.

Community teams tend to work from a local hospice and have doctors and nurses who can visit you in your own home. They give advice and guidance on pain and other symptoms, and can provide emotional support for you and your family. Your GP will know which community palliative care and hospice services are available in your area.

Sometimes it can help to spend a few days or weeks in a hospice having your pain, symptoms and other problems treated. Your community palliative care team or GP can arrange this for you. In the hospice, the doctors and nurses can often adjust the dose of or add in new painkillers more quickly than if you were at home. Once your pain is controlled, you can go home again to the care of your GP with the support of your community palliative care team.

Marie Curie nursing service
Marie Curie nurses help care for people who are having treatment to control their symptoms, such as pain, and want to stay in their own homes. They will stay for a period of time during the day and/or the night. Your district nurse or palliative care nurse will be able to give you more information about the Marie Curie nursing service in your area.
It’s important that you, your family, your GP and the specialist services know who is supervising your pain control and who you should contact if you have pain or other symptoms. You should be able to get help and advice, by telephone or in person during the day or night.

Painkillers

There are many painkillers available to treat different types and levels of pain, whether it’s mild, moderate or severe. Painkilling drugs are known as **analgesics**. Your medical team will aim to find the right combination of painkillers and other therapies to ensure that your pain is managed in the best possible way.

Some people with cancer have constant pain, so they need to take painkillers regularly to keep the pain under control. It’s important not to let pain build up until it’s severe. Severe pain can cause fear, anxiety and difficulty sleeping, which can make the pain worse and more difficult to control.

**Painkillers taken by mouth (oral medicines)**

Painkilling drugs are usually taken by mouth – either as tablets or capsules. For people who find it hard to swallow, many oral medicines are available as liquids and some can be dissolved in water.

**Other ways to take painkillers**

There are several other ways of taking painkillers that can be helpful if you can’t swallow or are being sick:

- **Feeding tube** – If you have a feeding tube, such as a PEG or RIG tube, some liquid or soluble painkillers can be given through the tube.
• **Skin patches** – These are stuck on to the skin. These are useful when your pain control is more settled. They only need to be changed every few days.

• **Buccal and sublingual medicines** – These are absorbed from the tissues in the mouth, so they don’t have to be swallowed. They are usually used for controlling breakthrough pain, as they work quickly.

• **Nasal medicines** – Some painkillers can be sprayed into the nose. These work best for breakthrough pain.

• **Suppositories** – These are inserted into the back passage.

• **Injection** – Many painkillers can be given by injection, either into a muscle or more usually under the skin (subcutaneously).

• **Infusion** – Some painkillers can be given by infusion over a period of time:

  **Subcutaneous infusion** A subcutaneous infusion involves giving a continuous dose of a drug or drugs into a fine needle or cannula (fine, plastic tube) that is placed just under the skin. A small portable pump known as a **syringe driver** (see page 30) is used to give the drugs this way.

  **Intravenous infusion using a patient-controlled analgesia (PCA) pump** After surgery, you may have a PCA pump to control your pain. A cannula is placed in a vein in your arm or the back of your hand and a thin tube is used to connect the cannula to the PCA pump. The pump has a handset that you press to give yourself a set dose of a painkiller, usually morphine. You can press the handset as often as needed to ensure your pain is controlled.
Epidural analgesia Occasionally painkillers may be given by infusion into the space that lies just outside the membranes surrounding the spinal cord. This is known as epidural analgesia. Sometimes the painkiller is given into the fluid around the spinal cord – this is known as intrathecal analgesia (see page 43). These specialised techniques are usually only used to control severe pain and are managed by anaesthetists, who specialise in pain control.

If you need to have your painkillers by injection or infusion, your doctor or nurse will discuss this with you.

Storing painkillers
It’s very important to store painkillers carefully. Make sure that they are properly labelled, and lock them up or keep them out of reach of children.

If you’re worried about forgetting to take them, write a note to yourself and put it somewhere you will see it rather than leaving the medicines out. Alternatively, you could ask your partner, relative or friend to remind you to take them, or you could create an alarm on your computer or mobile phone and title it ‘Painkillers’.

It may help you keep track of when your drugs are taken by writing them in your pain diary (see the centre of this booklet). Always return any unused medicines to a pharmacist, who can dispose of them properly.
Levels of pain control

There are different types of painkillers that are effective for mild, moderate or severe pain. These are set out in an ‘analgesic ladder’ (see below).

<table>
<thead>
<tr>
<th>Mild pain</th>
<th>Mild painkillers eg paracetamol or anti-inflammatory drugs eg ibuprofen (Brufen®, Neurofen®), diclofenac sodium (Voltarol®) or celecoxib (Celebrex®)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate pain</td>
<td>Weak opioid painkillers eg dihydrocodeine (DF118 Forte®, DHC Continus®), codeine phosphate or tramadol</td>
</tr>
<tr>
<td>Severe pain</td>
<td>Strong opioid painkillers eg morphine, oxycodone, fentanyl or diamorphine</td>
</tr>
</tbody>
</table>

The idea behind the analgesic ladder is that if a person’s pain is not controlled by the painkillers on one level, their doctor should prescribe a drug from the next level rather than try a different painkiller from the same group. For example, if you’re taking a mild painkiller such as paracetamol but are still getting pain, or if your pain gets worse, your doctor should prescribe a weak opioid (moderate) painkiller such as dihydrocodeine, codeine phosphate or tramadol. If the pain still isn’t controlled or if it increases, your doctor could then prescribe a strong opioid painkiller.

You don’t have to start with painkillers from the mild group – if you have moderate or severe pain when you first see your doctor, you can start by taking painkillers from the second or third step of the ladder.
Controlling cancer pain

Often, painkillers from two different groups will be used at the same time, as they work in different ways. For example, a strong painkiller such as morphine can be used at the same time as a mild painkiller such as paracetamol or ibuprofen.

At each step of the analgesic ladder, other drugs can also be used to help to control pain. These include bisphosphonates, steroids and anti-neuropathic drugs (see page 35). Although they are not painkillers, they can be used for specific types of pain.

Mild drugs for pain relief

Mild pain is treated with painkillers, such as paracetamol, and anti-inflammatory drugs.

Paracetamol can be used for a variety of mild pains. It can be bought over the counter from a chemist, and many supermarkets sell paracetamol. It has few side effects, but it’s important not to exceed the recommended dose, as higher doses can damage the liver. Paracetamol does not reduce inflammation.

Anti-inflammatory drugs help reduce inflammation and swelling, and are especially good at treating pain in the skin, muscle or bone. Ibuprofen can be bought from a pharmacist or from many supermarkets. Diclofenac sodium (Voltarol®) and celecoxib (Celebrex®) need to be prescribed by a doctor.

Check with your doctor or nurse before taking anti-inflammatory medicines, as they may interact with other medicines you are taking or may not be suitable for you. Always check the recommended dose on the packet and never take a higher dose than recommended.
Controlling cancer pain

Remember that other medicines or tablets that you can buy over the counter from a pharmacy or supermarket (eg cold cures) may also contain paracetamol or anti-inflammatory drugs such as aspirin or ibuprofen. These should not be taken in addition to other pain medicines unless advised by your doctor. Check with your pharmacist first before buying any other medicines.

Anti-inflammatory drugs can cause indigestion and may irritate the lining of the stomach, so it’s important to take them after a meal or snack. Your doctor may prescribe an additional tablet to help protect your stomach. If you’ve had previous problems with stomach ulcers, your doctor may advise you not to take them at all.

Weak opioid drugs for pain relief

Moderate pain is treated with weak opioid drugs such as dihydrocodeine (DF118 Forte®, DHC Continus®), codeine phosphate or tramadol.

These are often combined with paracetamol in a single tablet (eg co-codamol, which contains codeine and paracetamol, or co-dydramol, which contains dihydrocodeine and paracetamol). Combination painkillers have brand names such as Tylex®, Remedeine®, Solpadol®, Kapake® and Tramacet®. Most are only available on prescription from a doctor. There is a limit to the number of tablets that can be taken in one day because of the paracetamol content. If your pain isn’t controlled, it’s important to let your doctor know so that you can be switched to stronger painkillers.
Side effects of weak opioid drugs

- **Constipation** Painkillers containing dihydrocodeine and codeine can cause constipation. Usually you’ll need to take a laxative, which your doctor should prescribe for you (see page 25). Tramadol is less likely to cause constipation than codeine and dihydrocodeine.

- **Drowsiness** This type of painkiller may also cause drowsiness, which may be increased by alcohol (see page 24).

- **Dry mouth** Some drugs may make your mouth dry.

- **Sickness** Some people feel sick (nausea) and some may actually be sick (vomiting). If you feel sick, let your doctor know. Your doctor may prescribe anti-sickness medicines or suggest that you try an alternative painkiller.

Strong opioid drugs for pain relief

Severe pain is treated with strong opioid drugs.

Commonly used strong opioids are:

- morphine
- fentanyl
- oxycodone
- buprenorphine
- diamorphine.

Less commonly used strong opioids are:

- hydromorphone
- methadone
- alfentanil.
With this type of painkiller, it’s important for your doctor to find the most effective dose for you. Two people with the same type of cancer may need different doses of a drug, even if they’re at the same stage of their illness.

It’s common to start at a low dose and build up gradually to a dose that controls your pain. Other painkillers, such as paracetamol or anti-inflammatory drugs, can also be used with a strong opioid painkiller to help keep pain controlled.

If your pain increases or decreases, the dose of your opioid painkiller can be adjusted. You may only need a small dose increase to get your pain under control again. But if your pain is bad, your doctors may increase the dose by a larger amount – this is more likely to get on top of your pain than a smaller dose increase.

**Side effects of strong opioid painkillers**

It can take a few days to adjust to taking strong opioid painkillers. The most common side effects are:

- **Drowsiness** This usually passes within a few days once you’re used to the dose. Alcohol may increase drowsiness so if you do drink alcohol, it’s best to reduce your intake when you start taking strong painkillers. You can then gradually increase it if drowsiness isn’t a problem.

- **Feeling tired** Painkillers may also make you feel tired. You can talk to your GP about how this may affect you at home and at work. If you’re planning to drive or work with machinery, you should check with your GP before taking strong opioid painkillers. Don’t drive if you don’t feel fully alert or if your reactions are slowed.
• **Constipation** All strong opioid painkillers cause constipation. If you’re taking strong painkillers, you should also take a laxative throughout your treatment. Some laxatives soften stools and make them easier to pass while others stimulate the bowel to push the stools along more quickly. A combination of these two types is often best at preventing constipation.

• **Sickness** You may feel sick when you first start taking strong opioid painkillers, so you may need to take an anti-sickness (anti-emetic) drug for at least the first week of treatment. If you have sickness that doesn’t settle after 7 days, let your doctor know. Changing to another strong painkiller may help stop the sickness.

• **Dry mouth** These drugs can make your mouth dry, which can be a nuisance. This symptom can be relieved by drinking plenty of liquids. Chewing gum can also help.

• **Other effects** If the dose of a strong opioid painkiller is too high, it can cause symptoms such as marked drowsiness, confusion, hallucinations (seeing things that are not real), slow and deep breathing, and low blood pressure, which may make you feel dizzy or faint. Let your doctor know straightaway if you experience any of these effects.

Remember that although all strong opioid painkillers cause similar side effects, some may suit you better than others. If your pain is not well controlled, or if the side effects are a problem, tell your doctor or nurse so that your dose can be adjusted or another type of strong painkiller can be tried.
Specific types of strong opioid painkillers

Strong opioids such as morphine, fentanyl, oxycodone, buprenorphine and diamorphine are all commonly used, but hydromorphone, methadone and alfentanil are less commonly used. The text below describes the drugs, how they can be given and some possible side effects.

**Morphine**

Morphine can be taken in various ways:

- short-acting tablets (Sevredol®)
- long-acting tablets and capsules (Morphgesic® SR, MST Continus®, MXL®, Zomorph®)
- short-acting syrups (Oramorph®)
- long-acting granules to mix with water (MST Continus®)
- suppositories, which are usually short acting, inserted into the back passage (morphine)
- a short-acting injection (morphine sulphate).

A short-acting type of morphine is usually taken every four hours to begin with so that the dose can be adjusted until the pain is well controlled. It’s usually taken as a tablet or a liquid. Liquid morphine has a bitter taste that can be improved by mixing it with a fruit drink.

Once the right dose has been worked out, you will be able to take long-acting tablets, capsules or granules to mix with water. These release the morphine dose very slowly over a period of either 12 or 24 hours, depending on which type you are taking.
If you’re not able to swallow or are vomiting, morphine (as well as diamorphine and oxycodone) can be given by injection or as an infusion using a syringe driver (see page 30). Occasionally morphine suppositories are used.

**Side effects** Morphine has the usual side effects of strong painkillers mentioned on page 24. Some people find that the side effects of morphine can’t be controlled. They may have ongoing drowsiness or sickness that isn’t relieved by the usual medicines. In this case, it’s likely that your doctor will switch you to another strong opioid painkiller such as oxycodone or fentanyl. Side effects of painkillers vary from person to person and from one drug to another, so it’s usually possible to find another drug that suits you better.

**Fentanyl**

Fentanyl is usually given as a skin patch or as a buccal medicine (see page 17).

The patches (Durogesic DTrans®) look like waterproof plasters. They are stuck on to the skin, and the drug is released slowly through the skin. The patch is usually changed every three days, and the new patch is put on a different area of skin. The patches can be convenient, as you don’t need to remember to take tablets regularly. When the patch is first used, it takes around 12–24 hours for the fentanyl to reach its maximum level in the blood. During this time you’ll usually need to take a short-acting strong opioid such as morphine to keep the pain controlled.

There are two buccal preparations: a short-acting lozenge (Actiq®) and a buccal tablet (Effentora®). The lozenge and tablet are placed in the mouth between the cheek and the gum. They are absorbed from the soft tissues lining the cheek area
and act quickly to reduce pain. They work best for breakthrough pain (see page 8).

Fentanyl can also be given as a nasal spray or as a tablet that is placed under the tongue (sublingual).

**Side effects** The side effects are the same as for all strong painkillers, although the patches may also cause a slight skin rash where they are applied. For some people, fentanyl causes less constipation than other types of opioid drugs. When using the skin patch, warmth can make the fentanyl absorb more quickly through the skin. So if you have a high temperature, it’s important to let your doctor or nurse know immediately. It’s also important to avoid heating the skin patch, so care should be taken when going out in the sun, bathing, showering or using a heat pad near the patch.

**For the following drugs, the general side effects for strong opioid painkillers (see page 24) apply.**

**Oxycodone**
Oxycodone is given as short-acting capsules or liquid (OxyNorm®), which are taken every 4–6 hours, or long-acting tablets (OxyContin®), which are taken every 12 hours. It may be used if morphine causes too many side effects or doesn’t control the pain well enough.

Oxycodone can also be given by injection or continuously in a syringe driver (see page 30).
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Buprenorphine
Buprenorphine may be given as:

• a patch (Transtec®) that is changed every 3–4 days
• a patch (BuTrans®) that is changed every seven days
• a tablet (Temgesic®) that is dissolved under the tongue every 6–8 hours.

Diamorphine
Diamorphine may be used for people who can’t swallow and who need to have their painkillers given by injection or continuously by a syringe driver (see page 30).

Hydromorphone
Hydromorphone is available as short-acting capsules (Palladone®) and long-acting capsules (Palladone® SR).

Methadone
Methadone may be given as tablets or syrup or injection. It’s usually only given under close supervision from a specialist palliative care doctor or pain doctor. Methadone may be helpful for neuropathic pain (see page 8).

Alfentanil
Alfentanil is another strong painkiller that is only given by injection or subcutaneous infusion (see page 17). It’s more likely to be used if someone’s kidney function is poor.

We can send you fact sheets on managing side effects, including how to cope with a dry mouth.
**Syringe drivers**

A number of strong painkillers can be given by a syringe driver – these include morphine, oxycodone, diamorphine and alfentanil.

A syringe driver is a small portable pump that can be used to give you a continuous dose of your painkiller and other medicines. It’s often used if you’re vomiting or unable to swallow. Your doctor or nurse will let you know if you need a syringe driver.

A syringe driver is easy to set up. A syringe containing the painkiller is put into the driver and attached to a fine needle or cannula (fine, plastic tube) that is placed just under the skin (subcutaneously). A small dose of the drug is then released at a constant rate for as long as you need it. The syringe is usually changed every 24 hours by a nurse. This method of giving drugs is known as subcutaneous infusion (see page 17) and is very effective in keeping people free of pain.

Syringe drivers are battery powered and portable so you can be up and about as usual. They clip easily onto a belt, fit into a pocket or bum bag, or can be placed in a specially designed holster that fits under your arm. Other medicines, such as anti-sickness medicines, can also be given by the syringe driver.

Some people worry that if they have advanced cancer and are given painkillers or other medicines by a syringe driver, this could hasten their death. This isn’t true. A syringe driver is simply a different way of giving the same or similar drugs at the doses needed to control your symptoms.
Facts about painkillers for cancer pain

There are many myths about painkillers, especially strong ones such as morphine. These can often cause fears and worries and may lead to pain not being controlled. It can help to know some of the facts about painkilling drugs when you start taking them.

When should I take my painkillers?
You should start taking your painkillers when you have pain. Many people believe that they should put off using painkillers for as long as possible and that they should only get help when pain is becoming unbearable. This can mean that people are in pain unnecessarily and can also make the pain more difficult to control. There is no need to ‘save’ them until you’re very ill or your pain is severe.

Do I have to take my painkillers regularly?
When you’re taking painkillers, always be sure to take them regularly as prescribed by your doctor. The aim is to make sure that the pain control is constant.

If you’ve been given painkillers for breakthrough pain (see page 8), don’t wait for it to get really bad before you take them.

It’s important to let your doctors and nurses know if your pain isn’t controlled with your regular painkillers or if you get breakthrough pain. You may need to have your regular dose adjusted, or you may need to have a different painkiller. Remember that it can sometimes take a little time to get the right painkiller and the correct dose to control your pain.
Controlling cancer pain
If you have severe pain you may be given a strong painkiller, such as morphine, straightaway. This doesn’t mean that the cancer is more serious, just that the pain is severe. The dose can easily be adjusted as necessary if the pain gets better or worse. Being started on a strong painkiller doesn’t mean you will always need to take it. If your pain improves, you may be able to take a milder painkiller.

Will my painkillers be given in combination with any other medicines?
You may be given other medicines such as antidepressants, antiepileptics (drugs that prevent fits or seizures but are also used for neuropathic pain) and muscle relaxants to take with your painkillers. These medicines will also help to control your pain, but will do so in a different way from your painkillers. They are discussed on pages 35–37.

Will I become addicted to painkillers?
Many people who are prescribed strong opioid painkillers such as morphine ask if they will get addicted to it or if they will become confused and unable to look after themselves. This is unlikely to happen. People who become addicted to drugs usually initially choose to take them and then keep taking them because they have a psychological need. For example, they may crave feeling disconnected or ‘high’ when they take them. This is very different to someone who is in physical pain and needs to take the drug to control their pain.
What is the right dose of a strong opioid painkiller?
Unlike many other drugs, there is no standard dose for morphine or other strong opioid painkillers. The right dose is the one that controls your pain, and this varies from person to person.

Is there a maximum dose you can take?
If morphine or other painkillers are taken as prescribed, you will not overdose. There is no maximum dose for strong opioid painkillers. However, suddenly increasing the dose is dangerous, so never increase the dose or take extra doses without talking to your doctor first.

Can I just stop taking a strong opioid painkiller?
If you’re taking morphine or another strong opioid painkiller, it’s important that you don’t suddenly stop taking it. This is because as well as controlling pain, strong painkillers have other physical effects, and if they’re suddenly stopped, you may get withdrawal effects. These include diarrhoea, cramping pains in the stomach and bowel, sickness, sweating, restlessness and agitation.

If you want to stop taking a strong opioid painkiller, you should always talk to your doctor first. Your doctor will tell you how to gradually reduce the dose over a period of weeks or months so that you avoid these withdrawal effects.
Other helpful medicines (adjuvant drugs)

You may be prescribed other medicines, known as adjuvant drugs, to take along with your regular painkillers. These include:

- **Bisphosphonates**
  People who have pain from cancer that has spread to the bones may find drugs called bisphosphonates helpful. As well as helping to reduce pain, bisphosphonates can also strengthen the affected bones. Bisphosphonates may be given as a drip into a vein, usually once a month, or as tablets.

  **We can send you fact sheets about individual bisphosphonate drugs.**

- **Steroids**
  When pain is caused by a tumour pressing on or damaging a nerve, steroid drugs may help relieve this pressure and so reduce pain. They may be given alone or with other painkillers. Commonly used steroids are dexamethasone and prednisolone.

**Side effects**
Although they generally make you feel better, they may also increase your appetite. Steroids may make you put on weight, and they can increase your risk of getting infections.

The levels of sugar in your blood may also change temporarily. Tell your doctor or nurse if you become very thirsty and start going to the toilet to pass urine more often, as this may be due to an increase in your blood sugar level.
Some people find that steroids make them feel agitated or irritable because they make the mind more active. Steroids can make it more difficult to sleep, but this is less of a problem if they are taken in the morning. The side effects disappear gradually once treatment is over. Steroids can also cause indigestion and may irritate the lining of the stomach (sometimes causing bleeding), so it’s important to take them after a meal or snack. Your doctor may prescribe other tablets in addition to the steroids to help protect your stomach.

**We have a fact sheet on steroids that explains the side effects in detail.**

- **Antiepileptic and antidepressant drugs**
  Antiepileptic drugs such as gabapentin, pregabalin or carbamazepine or low-dose antidepressants such as amitriptyline can help reduce pain caused by nerve damage. This type of pain is called neuropathic pain (see page 8). The dose of these medicines may need to be gradually increased over a few days or weeks to control the pain, so it’s important to continue taking them even if they don’t work straightaway.

Some people worry that if they’re started on low doses of antidepressants for nerve pain, it’s because their doctor thinks they’re depressed, but this isn’t the case; research has shown that low doses of antidepressants are effective for nerve pain, but higher doses are needed to treat depression.

Some people find that the antidepressant amitriptyline can make them feel sleepier or slightly ‘hungover’. If this happens to you, let your doctor or nurse know. You should also make sure you take the dose at night to prevent you from feeling drowsy during the day.
• **Antibiotics**  
  When pain is due to an underlying infection, your doctor will likely prescribe you antibiotics to treat the infection.

• **Muscle relaxants**  
  If muscle spasms are making your pain worse, you may have a short course of a drug, such as diazepam (Valium®), baclofen (Lioresal®) or clonazepam (Rivotril®), to help relax the muscles.

**Daily drug schedule**

If you are taking several different drugs, you may find it helpful to draw up a chart that lists:

• the drugs you’re taking

• what they’re for

• their doses

• the time of day to take them.

Your doctor, nurse or pharmacist can help you do this, or they may be able to give you a chart to fill in this information. Make sure it has space for you to tick off each dose as you take it.

**Pill organisers**  
You may find it easier to have your drugs arranged in a container (called a ‘pill organiser’ or ‘dosette box’) labelled with the times you need to take them. Then you can always check that you’re up to date.

The aim is to make things as simple as possible. If you find it difficult to remember to take medicines several times a day, talk this over with your doctor. There may be other types of the same drug that can be taken less often.
You may find it useful to keep a diary of how well your pain and other symptoms are being controlled, as well as the painkillers you’re taking (see the centre of this booklet). This will help your medical team too. They will be able to see whether the doses of any of your painkillers need changing. If you don’t want to bother writing a full diary, just make a note if your pain comes back before your next dose of painkillers is due, and note when you need to take any extra doses.

**Using cancer treatments for pain control**

If pain is being caused by a tumour, treatments such as surgery, radiotherapy, chemotherapy or hormonal therapy may help to treat the tumour and reduce the pain.

**We can send you more information on all the treatments mentioned in this section.**

**Surgery** can be used to remove part, or all, of a tumour to relieve pressure on organs or a nerve. Sometimes, laser treatment can be used to reduce the size of the tumour.

**Radiotherapy** is sometimes used to shrink a tumour. This can reduce pain and other symptoms.

Radiotherapy is an effective way of controlling pain in the bones – especially the spine, thigh bones (femur), pelvis and ribs. It can help relieve pain and allows the bone to build up its strength again.

Usually only one or two sessions of radiotherapy are needed. The treatment doesn’t work immediately; it usually takes 7–10 days before it has an effect. You will need to keep taking your other painkillers during this time. The dose of radiotherapy
used to treat pain is quite low, and the treatment has very few side effects other than tiredness (fatigue).

**We have a booklet called *Coping with fatigue* that you may find useful.**

Sometimes **radioisotopes** may be used to help control pain in the bones. Radioisotopes are mildly radioactive substances that are taken up (absorbed) by the bones. The isotope is given as a liquid injected into a vein in the arm. When the isotope reaches the bone affected by cancer, it releases a dose of radiotherapy, which can help relieve pain. Strontium 89 is an example of a radioisotope. It can often take several weeks or even months for this type of treatment to work, so you’ll need to carry on with your ordinary painkillers in the meantime.

In some people, **chemotherapy** can shrink tumours to reduce pain and help people feel better, but it may cause side effects that are difficult to deal with. However, for others the treatment doesn’t work, and they will have the side effects of the treatment without the benefits.

Some chemotherapy drugs cause hair loss, and many of them can reduce your resistance to infection and cause tiredness, a sore mouth or diarrhoea. A few chemotherapy drugs can cause nerve pain.

Your doctor can discuss with you whether chemotherapy may be helpful for your pain. Ask your doctor how likely it is to work and what the side effects may be, so that you can decide whether chemotherapy would be helpful in your situation.

**Hormonal therapy** can be used to reduce pain for some types of cancer, such as breast and prostate cancer. Hormonal
Controlling cancer pain therapies can shrink these cancers by altering the levels of particular hormones in the body or by preventing certain hormones from attaching to cancer cells. There are many different types of hormonal therapy, and the side effects of each vary. However, hormonal therapies do not tend to cause severe side effects.

Your doctor can discuss with you whether hormonal therapies may be useful in controlling your pain, how likely the treatment is to work for you and what the possible side effects are.

Making decisions about treatment in these circumstances is always difficult. You may like to discuss the benefits and side effects of treatment with your doctor before making a decision about whether or not to have the treatment. You can also discuss these issues with our cancer support specialists on 0800 808 00 00 or you can contact some of the support organisations mentioned on pages 64–81.

Other methods of pain control

Other methods of pain control can be used on their own or in combination with painkillers. They include:

- transcutaneous electrical nerve stimulation (TENS)
- nerve blocks
- physiotherapy
- acupuncture
- relaxation techniques
- hypnotherapy
- meditation
• visualisation
• emotional support
• spiritual help.

**Transcutaneous electrical nerve stimulation (TENS)**

TENS machines send a weak electrical current through the skin. TENS works in two ways:

• It stimulates the nerves that carry non-painful messages to the brain. As these nerves are stimulated, they override and block the messages being carried in the pain nerves. This prevents painful messages from reaching the brain.

• It can also make the body release its own natural painkillers called endorphins.

TENS can help relieve cancer pain, especially if it’s in a specific part of the body. It’s common to use TENS alongside other treatments for pain.

TENS machines are usually only available for short-term loan on the NHS. Pain teams, physiotherapists and many palliative care teams can advise you on whether TENS is suitable for you and how to use it. Usually they will loan you a TENS machine so you can see how helpful it is before you decide whether to buy one. There are also many companies that sell TENS machines, but it’s always best to get specialist advice before buying and using a TENS machine.
How to use your pain diary

1. Begin by noting down the date when you use a new diary. You can fill in the diary as often as you need to. If your pain isn’t well controlled, you may want to fill it in every 1–2 hours, but if it’s better controlled, you can fill it in every 4–6 hours.

2. Note where the pain is on your body – you can use the body outlines on the back page of the diary. It could be in one area (ie your arm) or in multiple areas (ie your neck, shoulders and back).

3. Describe what the pain feels like using words such as dull, aching, pricking, sharp, sore, stabbing, comes and goes, constant, hot, cold and unbearable. See the back page of the diary for more words you can use to describe your pain.

4. Rate the level of pain on a scale of 0 to 10, where 0 means ‘no pain’ and 10 means ‘severe pain’ (see the back page of the diary).

5. Note down what medicines or pain control methods you used, as well as anything that made the pain better or worse.

All of this information will help you, your doctors and your nurses find the best pain control methods for you. Remember to photocopy the back page of the diary to go along with each pain diary you complete.
Keeping a record of your pain will help you discuss it with your doctors and nurses. Photocopy this diary before you fill it in so that you can use it as often as you need to. If you have pain in more than one place, you may want to use an additional copy of this diary.

<table>
<thead>
<tr>
<th>Time</th>
<th>Where is the pain?</th>
<th>What is the pain like?</th>
<th>Level of pain (where 0=none and 10=severe)</th>
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</thead>
<tbody>
<tr>
<td>1am</td>
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<td>2am</td>
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<td>11am</td>
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<td>12pm (noon)</td>
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<td>1pm</td>
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<tr>
<td>12am (midnight)</td>
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Keeping a record of your pain will help you discuss it with your doctors and nurses. You can use it as often as you need to. If you wish to use an additional copy of this diary.

<table>
<thead>
<tr>
<th>pain (where 0 = none and 10 = severe)</th>
<th>Medicines/pain control used?</th>
<th>What makes the pain better?</th>
<th>What makes the pain worse?</th>
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Where is the pain?

Is it in one part of your body or in more than one place?

You can use the diagrams like the one on the right to mark where your pain is.

If you have more than one pain you may want to label them (ie A, B, C).

What is the pain like?

You can use any of the following words to describe your pain:

- aching
- biting
- blunt
- burning
- cold
- comes and goes
- constant
- crushing
- cutting
- dragging
- dull
- excruciating
- frightful
- gnawing
- hot
- intense
- nagging
- nauseating
- niggling
- numb
- penetrating
- piercing
- pins and needles
- pricking
- radiating
- scratchy
- sharp
- shooting
- smarting
- sore
- spreading
- stabbing
- stinging
- tender
- throbbing
- tingling
- tiring
- unbearable.

Numbered pain scale

How bad is your pain? If you measured it on a scale of 0 to 10, how would you rate it (where 0=no pain and 10=the worst pain you’ve ever had)?
Nerve blocks
Nerve blocks may help relieve pain by preventing pain messages from getting to the brain (see page 5).

Nerves can be blocked using drugs such as local anaesthetics (sometimes given with steroids) or other chemicals such as alcohol or phenol. Local anaesthetics produce a short-lasting block. Although alcohol or phenol produce a longer-lasting block, they are less commonly used because of the side effects associated with them.

Specific nerve blocks may help specific pains. For example, pain from the pancreas may be reduced by something called a coeliac plexus block.

Occasionally epidural or intrathecal analgesia (see page 18) may be needed to control severe pain that is very difficult to control or if painkillers are causing unacceptable side effects. These techniques usually involve giving a continuous infusion of a painkiller (such as morphine, diamorphine or fentanyl) with or without a local anaesthetic by a fine tube that is inserted into the epidural or intrathecal space. The tube may be connected to an external pump or an internal pump, which is placed under the skin during a minor surgical procedure. The pumps are refilled with painkillers as required.

Nerve blocks are specialist techniques that are usually carried out by a pain team specialist (usually an anaesthetist) in your local hospital or at a specialist pain clinic. Your GP or hospital specialist can refer you to a pain team specialist, who usually works as part of a wider team of healthcare professionals known as a pain team (see page 14).
Controlling cancer pain

Physiotherapy
Pain may stop you from using the part of your body that hurts. This can lead to the deterioration of muscles and joint stiffness, which in turn may make pain and disability worse. Physiotherapy can help treat the problem and lead to an improvement in pain relief. Your GP will be able to refer you to a physiotherapist, who will be able to advise you on exercises that may help.

Acupuncture
It’s thought that acupuncture may work by stimulating the body to produce endorphins. It can be helpful for some people with cancer. A number of specialist NHS pain and palliative care teams offer acupuncture. Your GP or cancer specialist can refer you.

Relaxation techniques
Learning to relax and let go of your fears and anxieties – even if only for a short time each day – can play a useful part in your overall pain control. There are two main types of relaxation exercises:

• Physical exercises work on tension in your body. A technique called progressive muscle relaxation involves getting to know particular groups of muscles in the body and learning to tense and relax them. Once you can relax and contract stomach muscles, neck muscles and others individually or together, you can start using the technique during stressful periods to help reduce tension and therefore pain. When you have learned the basic techniques, you can use them to help with pain relief during more difficult times.

• Mental exercises, such as imagery exercises, help relax your mind. These can be particularly helpful if you find that anxiety is making your pain worse.
Try to find a quiet, warm, dimly lit, relaxing place where you will not be disturbed, then lie or sit in a well-supported position. You will get the maximum benefit from these techniques if you practise them for 5–15 minutes each day. Using relaxation tapes can be a great way to learn different exercises. You may want to just experiment until you find the best exercise for you, or you can ask your doctor if there is a healthcare professional, such as an occupational therapist or psychologist, who can help you find the technique that’s best for you.

**Hypnotherapy**
Hypnotherapy may help relieve cancer pain, but it is rarely effective on its own. However, self-hypnosis can play a part in helping you relax, which can help reduce the effect of emotional upset on your level of pain. Your GP may have a list of local therapists who provide hypnotherapy, or you can contact the National Register of Hypnotherapists and Psychotherapists for further information (see page 69).

**Meditation**
If you’re being treated for any mental illnesses, check with your doctor before using meditation. Although meditation can be helpful – for those with anxiety and depression, for example – it can also make problems worse if not properly supervised.

There are many different types of meditation, but they are all aimed at calming your mind and becoming at peace with yourself. You can try meditation by sitting quietly and being aware of your breathing, without trying to control it. Whenever you become aware that thoughts have come up in your mind, just come back to the awareness of your breathing. If you prefer, you can put an object in front of you and pay attention to that instead.
Meditation can be very difficult at first, and you may feel initially that you are getting worse as you become aware of how busy your mind is. However, it will become easier as you practise. It may help you let go of distressing or depressed thoughts for a period of time. It’s helpful to practise meditation once or twice a day and to have guidance from an experienced meditator. You can find details of meditation organisations in your local phone book or at your local library.

**Visualisation**
Visualisation (creating mental images) is a technique that helps you bring happy, relaxing pictures into your mind and use them to overcome some of your pain. By ‘seeing’ and ‘hearing’ images and sounds that bring you pleasure, you can, to some extent, shut out symptoms of pain and discomfort.

You may find meditation, visualisation, relaxation or a combination of these techniques helpful in relieving your pain. Methods vary but the overall aim is the same: to reduce stress and other emotional factors that may be making your pain worse. You can either go to classes to learn these techniques or buy tapes, CDs, records or books. Your GP may know of local relaxation classes, some of which are especially suited to the needs of people with cancer.

*Meditation, relaxation and visualisation are explained more fully in our booklet Cancer and complementary therapies.*

**Emotional support**
It’s natural to feel a whole range of powerful emotions, including depression, fear and anxiety, when dealing with cancer. These emotions can make pain worse.
It’s important that you are given emotional support. It helps if you acknowledge your feelings and don’t bottle things up.

**Our booklet The emotional effects of cancer discusses ways of dealing with emotions.**

You may have anxious feelings from time to time and it may help to talk through your feelings with your partner, a close friend or relative.

If you feel anxious most of the time or you don’t feel able to talk to someone close to you (perhaps because it upsets you both too much), let your GP know. Your GP can put you in touch with a counsellor. You could also contact one of the counselling organisations listed on pages 68–69 or you can speak to our cancer support specialists on 0808 808 00 00, who may be able to give you contact details of local support groups.

Sometimes your GP may suggest that you take either an antidepressant or a sedative drug such as diazepam to help improve your mood or reduce anxiety.

**Spiritual help**

Serious illness can force people to take life more seriously, to question its meaning and to stop taking things for granted. Some people who have religious beliefs may find their faith greatly shaken by their cancer diagnosis. Even people who have never been regular worshippers may experience spiritual as well as emotional pain. People often ask questions such as, ‘Is there life after death?’ and ‘Why should the people I love suffer?’ Unanswered questions such as these, which relate to fundamental beliefs, can cause great emotional and spiritual pain that can increase the experience of physical pain.
It’s often hard to accept or understand why an illness like cancer happens to you or to those you love. People often have feelings of anger and guilt, and you may worry about how the cancer will affect your family now and in the future. Sometimes the strength of these emotions may make you feel isolated and frightened, and you may withdraw from family and friends. It can help to talk to someone about these feelings.

Some people find great comfort in religion at this time, and it may help to talk to a local minister, hospital chaplain or other religious or spiritual leader. If you don’t feel that this is the right sort of support for you, talking with family and friends, a counsellor or someone from a cancer support organisation may help. Details of organisations that provide counselling are on pages 68–69.

**How other people can help you**

Many people assume that drugs or other treatments are the only way to control cancer pain. In fact, they are only one part of treatment. Sometimes the simplest ways of making you feel better are overlooked. There are a lot of things, on their own or together with medical treatment, that you and other people can do to make you feel better.

**Are you comfortable?**
The way you sit or lie down can affect your pain. What may feel comfortable at first may be painful 15 or 20 minutes later. Family or friends can help you change position as often as you need. This will also reduce the risk of your skin becoming sore as a result of sitting or lying still in one position for long periods.

Bedding may need to be tidied or changed, too. You may feel a lot better when you get back into a cool bed with fresh
Controlling cancer pain

bed linen. V-shaped pillows or supports can help reduce backache and neckache, and a bed cradle can keep the weight of blankets off weak limbs.

Your district nurse may be able to provide you with a special mattress and cushions. Other people from your care team, such as a physiotherapist or occupational therapist, can provide special equipment to help with movement and sitting.

**Hot or cold**
Heat pads and warm baths can relax muscles, reduce joint stiffness and help relieve aches and pains. Ice packs can help relieve pain where there is inflammation and swelling. Some people find that alternating heat with cold is more helpful for controlling their pain.

Care should always be taken to protect the skin from burns when using heat pads and ice packs. Heat pads should be used with a fleece cover, and ice packs should be wrapped in a towel before placing them near the skin. Heat shouldn’t be used on body areas that are already inflamed or swollen, as it can make the swelling worse.

**Massage**
Gentle massage can help relieve aching backs or limbs. By rubbing the painful area, you will help reduce the number of painful messages reaching the brain, and you will also help the muscles relax. Unscented oils and lotions can also help keep your skin soft and supple.

Massage and the use of oils and lotions should be avoided in areas that are either being treated with radiotherapy or have recently been treated. You may also need to be careful if you have cancer in the bones, as even gentle rubbing on those
areas may make the pain worse. If the number of platelets in your blood is low, you will be more likely to bruise. In this case, you may be advised not to have some types of massage until the number of platelets in your blood has increased.

**Occupying your mind**
Watching TV, reading, playing computer games, listening to music or chatting to a friend will not make your pain go away, but it can help distract you, at least for a time. Sitting in a chair or lying in bed with nothing to do can become depressing, and even short periods of entertainment can help you feel better and help you cope better with your pain. Short, regular visits from friends and relatives are probably better than longer ones. They are less tiring, help break up the day and are something to look forward to.

**Practical support and information**
You may be anxious about your treatment or worried about coping at home. You may have financial problems. Often, friends or relatives can help by getting more information from doctors and nurses or by finding out about services that can help. Sometimes there is little that they can say or do, but just being there to listen and understand can be enough.

If you’re not sure where to turn to for more information or would like to know more about services that can help, you could call our cancer support specialists on 0808 808 00 00. They will be able to listen to you and can help point you to the services that can help.
Control of other cancer symptoms

People with cancer may have a wide variety of symptoms – some of them due to cancer, others caused by its treatment. Trying to cope with other symptoms may make it more difficult to cope with your pain. Often, other symptoms can be relieved by medical or non-medical treatments or by a combination of both. If your other symptoms are well controlled, this can help you deal more effectively with your pain.

We can send you a booklet on controlling the symptoms of cancer.

Tiredness (fatigue)

Pain may feel worse if you’re very tired, and fatigue (feeling exhausted all or most of the time) is a common and difficult problem for people with cancer. It can have a number of different causes. Fatigue may be due to your treatment, the cancer or other symptoms you may have.

There are different ways of treating fatigue depending on the cause, so always let your doctor know how you’re feeling. There are also steps you can take to make it easier to cope, such as saving your energy for the things that are most important to you. This may mean being more willing to accept help from other people or making simple changes to the way you do things around the home.
Some research has found that exercise and keeping active can help raise energy levels, but it’s important that you don’t feel that you have to exercise or keep going if you are too tired or are in pain.

*We have a booklet called *Coping with fatigue*, which gives useful information and suggestions on how to deal with this problem.*

**Sleep disturbances**

Most people with cancer have trouble sleeping at some time during their illness. Sleeplessness may be due to anxiety, fears about the future or disturbed sleep patterns. If you feel tired and doze during the day, you’re likely to find it harder to sleep at night.

Pain is another reason for disturbed sleep, but it can be helped with good pain control. Although getting to sleep may be the hardest thing to do, you may also notice that you wake early – often around 3am or 4am – and find it difficult to get back to sleep if you’re depressed. Most sleeping tablets only work for a few hours to help people get to sleep, so they will not help if you wake in the early hours of the morning.

Relaxation, counselling and simply talking through the cause of any anxiety may be helpful for some people. It can help if you establish a regular routine at bedtime and go to bed at the same time each night. Try a warm, milky drink before bed. Have a warm bath with a few drops of lavender or geranium oil to help you relax, or sprinkle a couple of drops on your pillow.
If you can’t sleep or if you wake up early, try to relax and not worry about it. Rather than lying in bed tossing and turning, get up and watch TV or read a book. Wait until you feel tired again and then go back to bed. Story tapes or CDs, which are stocked in most public libraries, may also help you fall asleep.

Older people and people who have not been very physically active during the day need less sleep at night. If you are napping during the day and having problems sleeping at night, it may mean you do not need so much rest. See if it helps to limit yourself to one rest or sleep each day.

If you’re taking steroid tablets, these can interfere with your sleep if taken in the evening or at bedtime. You may find it better to take steroids during the morning, unless your doctor advises otherwise.

Sometimes a short course of sleeping pills may help re-establish a more normal sleeping pattern and can get you over a particularly difficult patch.
Practical support

If your pain means that you can’t move around easily, you may need specialist equipment or people to help you in your daily life.

The British Red Cross (see page 75) has a branch in every county, and their volunteers can help you in many ways, including shopping, posting letters and changing library books. They also lend equipment, such as wheelchairs and commodes, for nursing someone at home, and they can provide you with a trained volunteer helper if you need help going places such as the hospital.

If your pain is causing any kind of disability, there are many organisations that provide equipment that can help you.

The Disabled Living Foundation (see page 76) runs a helpful information service. It also has specialist advisers and occupational therapists who can give personal advice on aids and specialist equipment, including special cutlery, walking aids and wheelchairs. DIAL UK also gives information and advice to disabled people (see page 76).

Good neighbour scheme

Some areas have a ‘good neighbour scheme’. The schemes can organise help – for example, shopping, providing company or offering transport – for someone living locally every so often. These schemes are usually run by the social services or local community organisations. Some are only available to people living alone. Look for ‘Council for Voluntary Service’ or ‘Volunteer Bureau’ in the phone book or online.
Financial help and benefits

If you are employed and unable to work, your employer can pay you Statutory Sick Pay (SSP) for a maximum of 28 weeks. If you are still unable to work after this period, you may be able to claim Employment and Support Allowance (ESA). There are two parts to ESA: a contributory part, which is dependent on how much national insurance you have paid, and a means-tested part, which is dependent on your income and savings. You may get either or both parts.

ESA is paid at a basic rate for the first 13 weeks. During this time, you’ll have to take part in a work capability assessment and attend a work-focused interview. After the 13-week period you’ll be assessed and placed into one of two groups.

If you are found to have limited capability for work you’ll be placed in the support group, and if you are found not to have limited capability for work you’ll be placed in the work-related activity group.

If you are receiving radiotherapy or intravenous (by injection into a vein) chemotherapy, you will automatically be assessed as having limited capability for work and will be placed in the support group. People in the work-related activity group will have to attend six more work-focused interviews, which aim to help them get back into work.

An additional payment will be paid to anyone in the support group, and a small additional payment will be paid to anyone in the work-related activity group.
If you are self-employed you can claim ESA as long as you have paid the correct level of national insurance contributions. People who have not paid these may qualify for ESA under the means-tested route.

If you are ill and not able to claim, remember to ask your GP for a medical certificate for the period of your illness. If you are in hospital, ask your doctor or nurse for a certificate to cover the time that you are an inpatient. This is necessary if you need to claim a benefit.

You may qualify for Disability Living Allowance (DLA) if you are under 65 or for Attendance Allowance (AA) if you are over 65.

There is a fast-track claim for people who may not live longer than six months. People who claim under this ‘special rule’ need to get their doctor to complete a form for either benefit. It’s impossible to tell exactly how long someone with cancer may live, and many people with advanced cancer may be entitled to this benefit. Special rules payments of AA and the DLA care component are reviewed after three years.

**Information about benefits and financial help**

For more information about benefits and financial support, please call us on **0808 808 00 00**. You may also find our booklet *Help with the cost of cancer* useful.

You can find out more about benefits from your local Citizens Advice or by calling the Benefit Enquiry Line on **0800 882 200**. You can also visit the Department for Work and Pensions website at [dwp.gov.uk](http://dwp.gov.uk)
Direct payments

If your assessment shows you need social services, you may be entitled to get direct payments from your local authority. This means that you are given payments to organise social services yourself, rather than the local social services paying for and organising them for you. You can get more information about direct payments from the Department of Health website at dh.gov.uk or from your local authority.

Insurance

After having treatment for cancer, it can be more difficult to get life or travel insurance. An independent financial adviser (IFA) can help you with life insurance and can find the best deal for your particular situation. You can find a local IFA by referral from family or friends, by looking in your phone book or by contacting The Personal Finance Society (see page 71) or Independent Financial Advisers Promotions (see page 70).

We can send you more information about travel and cancer. We also have a booklet about getting travel insurance, which has a list of companies who offer insurance to people with medical conditions including cancer. This information is also on our website.
How we can help you

Cancer is the toughest fight most of us will ever face. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

Get in touch

Macmillan Cancer Support
89 Albert Embankment,
London SE1 7UQ
Questions about cancer?
Call free on 0808 808 00 00
(Mon–Fri, 9am–8pm)
www.macmillan.org.uk
Hard of hearing?
Use textphone
0808 808 0121 or Text Relay.
Non-English speaker?
Interpreters are available.

Macmillan Support Line
Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. Call us on 0808 808 00 00 or email us via our website, macmillan.org.uk/talktous

Information centres
Our information and support centres are based in hospitals, libraries and mobile centres, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at macmillan.org.uk/informationcentres

Clear, reliable information about cancer

We can help you by phone, email, via our website and publications or in person. And our information is free to everyone affected by cancer.
Publications
We provide expert, up-to-date information about different types of cancer, tests and treatments, and information about living with and after cancer. We can send you free information in a variety of formats, including booklets, leaflets, fact sheets, and audio CDs. We can also provide our information in Braille and large print.

You can find all of our information, along with several videos, online at macmillan.org.uk/cancerinformation

Review our information
Help us make our resources even better for people affected by cancer. Being one of our reviewers gives you the chance to comment on a variety of information including booklets, fact sheets, leaflets, videos, illustrations and website text.

Need out-of-hours support?
You can find a lot of information on our website, macmillan.org.uk
For medical attention out of hours, please contact your GP for their out-of-hours service.

Someone to talk to
When you or someone you know has cancer, it can be difficult to talk about how you’re feeling. You can call our cancer support specialists to talk about how you feel and what’s worrying you.

We can also help you find support in your local area, so you can speak face-to-face with people who understand what you’re going through.
**Professional help**

Our Macmillan nurses, doctors and other healthcare and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until they no longer need this help.

You can ask your GP, hospital consultant, district nurse or hospital ward sister if there are any Macmillan professionals available in your area, or call us.

**Support for each other**

No one knows more about the impact cancer has on a person’s life than those who have been affected by it themselves. That’s why we help to bring people with cancer and carers together in their communities and online.

**Support groups**

You can find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](http://macmillan.org.uk/selfhelpandsupport)

**Online community**

You can also share your experiences, ask questions, get and give support to others in our online community at [macmillan.org.uk/community](http://macmillan.org.uk/community)
Financial and work-related support

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. Some people may have to stop working.

If you’ve been affected in this way, we can help. Call the Macmillan Support Line and one of our cancer support specialists will tell you about the benefits and other financial help you may be entitled to.

We can also give you information about your rights at work as an employee, and help you find further support.

Macmillan Grants
Money worries are the last thing you need when you have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much-needed break.

Find out more about the financial and work-related support we can offer at macmillan.org.uk/financialsupport

Learning about cancer

You may find it useful to learn more about cancer and how to manage the impact it can have on your life.

You can do this online on our Learn Zone – macmillan.org.uk/learnzone – which offers a variety of e-learning courses and workshops. There’s also a section dedicated to supporting people with cancer – ideal for people who want to learn more about what their relative or friend is going through.
Other useful organisations

**Action on Pain**  
PO Box 134, Shipdham, Norfolk IP25 7XA  
**Helpline** 0845 6031593  
(Mon–Fri, 10am–4pm)  
**Email** aopisat@btinternet.com  
[www.action-on-pain.co.uk](http://www.action-on-pain.co.uk)  
Provides support and advice for people with chronic pain. Run entirely by volunteers, many of whom either have or are affected by chronic pain. Provides a helpline, produces eight informative booklets and has a UK-based Mobile Information Unit.

**British Pain Society**  
3rd floor, Churchill House, 35 Red Lion Square, London WC1R 4SG  
**Tel** 020 7269 7840  
**Email** info@britishpainsociety.org  
[www.britishpainsociety.org](http://www.britishpainsociety.org)  
Can provide a list of local pain clinics, a list of self-help groups and the booklet *Understanding and Managing Pain: Information for Patients* as well as several leaflets on managing pain.

**Pain Association Scotland**  
Suite D, Moncrieff Business Centre, Friarton Road, Perth PH2 8DG  
**Freephone** 0800 783 6059  
**Email** info@painassociation.com  
[www.painassociation.com](http://www.painassociation.com)  
Deals with the development and delivery of the self-management training approach to chronic pain throughout Scotland. Offers self-management meetings that are staff-led and held in an interactive, friendly atmosphere. Provides an increased understanding of ways to improve the quality of your life despite your pain, and relaxation and movement sessions.

**Pain Concern**  
1 Civic Square, Tranent EH33 1LH  
**Helpline** 0844 499 4676  
(Mon–Fri, 10am–4pm)  
**Email** info@painconcern.org.uk  
[www.painconcern.org.uk](http://www.painconcern.org.uk)  
Provides information and
support for people with pain as well as their carers, family and friends. Free fact sheets and leaflets to help you manage your pain. Has a quarterly magazine, a ‘Listening Ear’ helpline, which gives you the chance to talk to another person who has or has had pain, and an online forum.

**Pain Relief Foundation**  
Clinical Sciences Centre, University Hospital Aintree, Lower Lane, Liverpool L9 7AL  
**Tel** 0151 529 5820  
**Email** secretary@painrelieffoundation.org.uk  
[www.painrelieffoundation.org.uk](http://www.painrelieffoundation.org.uk)  
Promotes research into the causes of, and treatments for, chronic pain. Offers an information service to people with pain and has leaflets about chronic pain conditions.

**Complementary therapies**

**British Acupuncture Council**  
63 Jeddo Road, London W12 9HQ  
**Tel** 020 8735 0400  
**Email** from the website  
[www.acupuncture.org.uk](http://www.acupuncture.org.uk)  
The main regulatory body for the practice of acupuncture. A Register of Practitioner Members is published annually. A copy can be obtained for £5. Alternatively, a list of local practitioner members of the BAcC can be posted free of charge or obtained from the website.

**The British Complementary Medicine Association (BCMA)**  
PO Box 5122, Bournemouth BH8 0WG  
**Tel** 0845 345 5977  
**Email** office@bcma.co.uk  
[www.bcma.co.uk](http://www.bcma.co.uk)  
An umbrella organisation of complementary medicine therapists and organisations that holds a register of qualified therapists who are all members of the BCMA and adhere to its code of ethics.
British Medical Acupuncture Society
BMAS House, 3 Winnington Court, Northwich, Cheshire CW8 1AQ
Tel 01606 786 782
Email admin@medical-acupuncture.org.uk
www.medical-acupuncture.co.uk
A registered charity established to encourage the use and scientific understanding of acupuncture within medicine. It seeks to enhance the education and training of suitably qualified practitioners and to promote high standards of working practices in acupuncture. Their website provides contact details for practitioners.

Institute for Complementary Medicine
Can-Mezzanine, 32–36 Loman Street, London SE1 0EH
Tel 0207 922 7980
Email info@icnm.org.uk
www.i-c-m.org.uk
Keeps a register of professional practitioners who work to a code of ethics and practice, and have full practitioner insurance. You can search for a practitioner via the website.

General cancer support organisations

Cancer Black Care
79 Acton Lane, London NW10 8UT
Tel 020 8961 4151
(Mon–Fri, 9.30am–4.30pm)
Email info@cancerblackcare.org
www.cancerblackcare.org
Offers a variety of information and support for people with cancer from ethnic
communities, their friends, carers and families. Welcomes people from different ethnic groups including African, Asian, Turkish and African-Caribbean communities.

**Irish Cancer Society**  
43–45 Northumberland Road, Dublin 4, Ireland  
**Cancer helpline**  
1800 200 700 (Mon–Thurs, 9am–7pm, Fri, 9am–5pm)  
**Email** helpline@irishcancer.ie  
**www.cancer.ie**  
Operates Ireland’s only freephone cancer helpline, which is staffed by qualified nurses trained in cancer care.

**Maggie’s Cancer Caring Centres**  
8 Newton Place, Glasgow G3 7PR  
**Tel** 0300 123 1801  
**Email** enquiries@maggiescentres.org  
**www.maggiescentres.org**  
Located throughout the country, Maggie’s Centres are places to turn to for anyone affected by cancer. You can access information, benefits advice and emotional or psychological support. You don’t have to make an appointment or be referred, and everything is free of charge.

**Penny Brohn Cancer Care** (formerly Bristol Cancer Help Centre)  
Chapel Pill Lane, Pill, Bristol BS20 0HH  
**Helpline** 0845 123 2310 (Mon–Fri, 9.30am–5pm)  
**Email** helpline@pennybrohn.org  
**www.pennybrohncancercare.org**  
A national charity that works in combination with medical treatment to offer a unique combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

**Tak Tent Cancer Support – Scotland**  
Flat 5, 30 Shelley Court, Gartnavel Complex, Glasgow G12 0YN  
**Tel** 0141 211 0122  
**Email** taktent4u@gmail.com  
**www.taktent.org**
Offers information and support for cancer patients, their families and friends and to healthcare professionals. Runs a monthly network of support groups across Scotland. Also provides counselling and complementary therapies.

**Tenovus**  
9th Floor, Gleider House, Ty Glas Road, Llanishen, Cardiff CF14 5BD  
**Freephone helpline** 0808 808 1010  
**Tel** 029 2076 8850  
**Email** post@tenovus.com  
**www.tenovus.org.uk**  
Provides a variety of services to people with cancer and their families, including counselling and a freephone cancer helpline.

**The Ulster Cancer Foundation**  
40–44 Eglantine Avenue, Belfast BT9 6DX  
**Freephone helpline** 0800 783 3339  
**Helpline email** infocis@ulstercancer.org

**Tel** 028 9066 3281  
**Email** info@ulstercancer.org  
**www.ulstercancer.org**  
Provides a variety of services for people with cancer and their families, including a free telephone helpline, which is staffed by specially trained nurses with experience in cancer care.

**Counselling, bereavement and emotional support**

**British Association for Counselling and Psychotherapy (BACP)**  
BACP House, 15 St John’s Business Park, Lutterworth, Leicestershire LE17 4HB  
**Tel** 01455 883 300  
**Email** bacp@bacp.co.uk  
**www.bacp.co.uk**  
Aims to promote awareness of counselling and increase availability, and to signpost people to appropriate counselling services. Has a database on its website where you can search for a qualified counsellor.
National Register of Hypnotherapists and Psychotherapists
1st Floor, 18 Carr Road, Nelson, Lancashire BB9 7JS
Tel 01282 716 839
Email admin@nrhp.co.uk
www.nrhp.co.uk
Keeps an up-to-date database of hypnotherapists throughout the United Kingdom and overseas, and provides a free referral service for those seeking a reputable practitioner. You can search the register via the website.

The United Kingdom Council for Psychotherapy (UKCP)
2nd Floor, Edward House, 2 Wakley Street, London EC1V 7LT
Tel 020 7014 9955
Fax 020 7014 9977
Email info@ukcp.org.uk
www.psychotherapy.org.uk
A membership organisation, with more than 75 training and listing organisations, and more than 6,600 individual practitioners. UKCP holds the national register of psychotherapists and psychotherapeutic counsellors, listing those practitioner members who meet exacting standards and training requirements.

Youth Access
1–2 Taylors Yard, 67 Alderbrook Road, London SW12 8AD
Tel 020 8772 9900
(Mon–Fri, 9.30am–1pm and 2–5.30pm)
Email admin@youthaccess.org.uk
www.youthaccess.org.uk
A national membership organisation for young people’s information, advice, counselling and support services. It is the largest provider of advice and counselling services in the UK, dealing with more than one million enquiries a year on issues as diverse as sexual health, mental health, relationships, homelessness and benefits. Find your local Youth Access service from the website.
Money or legal advice and information

Benefit Enquiry Line
2nd Floor, Red Rose House, Lancaster Road, Preston, Lancashire PR1 1HB
Freephone 0800 882 200
Free textphone 0800 243 355
Email BEL-Customer-Services@dwp.gsi.gov.uk
Provides advice about benefits, and can also provide help with the completion of some disability-related claim packs.

Citizens Advice
Provides free, confidential, independent advice on a variety of issues including financial, legal, housing and employment. Find contact details for your local office in the phone book or at citizensadvice.org.uk Find advice for the UK online, in many languages, at adviceguide.org.uk

Citizens Advice Scotland
www.cas.org.uk

Independent Financial Advisers Promotion (IFAP)
2nd Floor, 117 Farringdon Road, London EC1R 3BX
Tel 0800 085 3250
Email ifacontact@unbiased.co.uk
www.unbiased.co.uk
Search for details of local member independent financial advisers via the consumer hotline and online searches at unbiased.co.uk and moneymadeclear.fsa.gov.uk

Macmillan Telephone Benefits Advice Service
Can help with checking the benefits you may be entitled to, filling in forms, accessing grants and giving general financial information. You can speak to one of the cancer support specialists by telephoning the helpline on 0808 808 00 00. For more information on this service, visit the Macmillan website at macmillan.org.uk/HowWeCanHelp/FinancialSupport/FinancialSupport.aspx
You can also find your local Macmillan Benefits
Advice Service for face-to-face help at macmillan.org.uk/HowWeCanHelp/FinancialSupport/BenefitsAdvisersMacmillanLocalBenefitsAdvisers.aspx

The Law Society
113 Chancery Lane,
London WC2A 1PL
Tel 0870 606 2555
Email info.services@lawsociety.org.uk
www.lawsociety.org.uk
Represents solicitors in England and Wales and can provide details of local solicitors.

Law Society of Scotland
26 Drumsheugh Gardens,
Edinburgh EH3 7YR
Tel 0131 226 7411
Email lawscot@lawscot.org.uk
www.lawscot.org.uk

Law Society of Northern Ireland
96 Victoria Street,
Belfast BT1 3GN
Tel 028 9023 1614
Email info@lawsoc-ni.org
www.lawsoc-ni.org

National Debt Line
(England, Wales and Scotland)
Tricorn House, 51–53 Hagley Road, Edgbaston,
Birmingham B16 8TP
Freephone: 0808 808 4000
(Mon–Fri, 9am–9pm, Sat, 9.30am–1pm)
Email from the website
www.nationaldebtline.co.uk
A national telephone helpline for people with debt problems. The service is free, confidential and independent, and the call handlers also distribute free self-help materials.

Personal Finance Society – ‘Find an Adviser’ service
42–48 High Road, South Woodford, London E18 2JP
Tel 020 8530 0852
Email info@findanadviser.org
www.findanadviser.org
The UK’s largest professional body for independent financial advisers. Use the ‘Find an Adviser’ website to find qualified financial advisers in your area.
Controlling cancer pain

**Turn2Us**
1 Derry Street,
London W8 5HY
**Helpline** 0808 802 2000
(Mon–Fri, 8am–8pm)
**Email** info@turn2us.org.uk
**www.turn2us.org.uk**
A charity providing an online service to help people in financial need in the UK. Use its website for free to see information about the benefits and grants available to you from both statutory and voluntary organisations. You can often apply for support directly from the website.

**Support for carers**

**Carers Direct**
PO Box 4338,
Manchester M61 0BY
**Helpline** 0808 802 0202
(Mon–Fri, 8am–9pm, weekends, 11am–4pm)
**Email** from the website
**www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx**
Aims to offer all the information you should need as a carer to access the financial help you’re entitled to, as well as advice on getting a break from caring, going to work and much more.

**Carers UK**
20 Great Dover Street,
London SE1 4LX
**Tel** 020 7378 4999
**Carers line** 0808 808 7777
(Wed and Thurs, 10am–12pm and 2–4pm)
**Email** info@carersuk.org
**www.carersuk.org**
Offers information and support to carers. Can put people in contact with local support groups. Has national offices for Scotland, Wales and Northern Ireland:

**Carers Scotland**
The Cottage, 21 Pearce Street,
Glasgow G51 3UT
**Tel** 0141 445 3070
**Email** info@carerscotland.org
**www.carerscotland.org**

**Carers Wales**
River House, Ynsbridge Court, Gwaelod-y-Garth,
Cardiff CF15 9SS
**Tel** 029 2081 1370
**Email** info@carerswales.org
**www.carerswales.org**
Controlling cancer pain

Carers Northern Ireland
58 Howard Street,
Belfast BT1 6PJ
Tel 028 9043 9843
Email info@carersni.org
www.carersni.org

A charity dedicated to the provision of short breaks for carers within their own homes. Has services throughout Scotland that provide practical support for carers of all ages.

Crossroads Care
10 Regent Place, Rugby,
Warwickshire CV21 2PN
Tel 0845 450 0350
Email from the website
www.crossroads.org.uk
Services are provided through a network of local independent charities across England and Wales, each offering Crossroads’ core service where a trained carer support worker comes into the home to take over the caring responsibilities. Each charity has its own funding and can therefore provide additional services according to funding and demand at a local level.

Crossroads Caring Scotland
24 George Square,
Glasgow G2 1EG
Tel 0141 226 3793
Email info@crossroads-scotland.co.uk
www.crossroads-scotland.co.uk

A Northern Ireland-based charity providing respite for carers by giving them a much-needed break, providing peace of mind that their loved one is well taken care of by a Crossroads care attendant.

Crossroads Caring for Carers (Northern Ireland)
7 Regent Street,
Newtownards, Co Down,
Northern Ireland BT23 4AB
Tel 028 9181 4455
Email mail@crossroadscare.co.uk
www.crossroadscare.co.uk

The largest provider of carers’ services.

The Princess Royal Trust for Carers
Unit 14, Bourne Court,
Southend Road, Woodford Green, Essex IG8 8HD
Tel 0844 800 4361
Email info@carers.org
www.carers.org and www.youngcarers.net
support services in the UK. Through its network of 144 independently managed Carers’ Centres, 85 young carers’ services and interactive websites, the trust currently provides information, advice and support services to more than 400,000 carers, including approximately 25,000 young carers.

Young Carers Initiative
The Children’s Society
Edward Rudolf House,
Margery Street,
London WC1X 0JL
Tel 0845 300 1128
Email supportercare@childrenssociety.org.uk
www.youngcarer.com
Works nationally to promote good practice for young carers and their families. From the website you can search for local young carers projects in the UK and also access information for young carers about health, school, the internet, being heard, who’s who and The Purple News young carers newsletter.

Young Carers Net (YCNet)
Princess Royal Trust for Carers
Unit 14, Bourne Court,
Southend Road, Woodford
Green, Essex IG8 8HD
Tel 0844 800 4361
Email youngcarers@carers.org
www.youngcarers.net
Provides information, advice and support for young carers and aged 18 and under in the UK who help to look after someone in their family who has an illness, disability, drug/alcohol addiction or mental health condition. Also has an online discussion forum.

Equipment and advice on living with disability

Assist UK
Redbank House, 1 Portland Street, Manchester M1 3BE
Tel 0161 238 8776
Email general.info@assist-uk.org
www.assist-uk.org
An independent voluntary organisation with a network of Disabled Living Centres
throughout the UK. Centres offer advice and a variety of products and equipment designed to make life easier for people who have difficulty with daily activities.

**The Blue Badge Scheme (Department of Transport) Advice Line** 020 7944 2914 or 0161 367 0009  
[www.dft.gov.uk/transportforyou/access/bluebadge](http://www.dft.gov.uk/transportforyou/access/bluebadge)  
Provides a national arrangement of parking concessions for people with severe walking difficulties who travel either as drivers or passengers. It allows badge holders parking concessions so they can park close to their destination. The scheme operates throughout the UK and is administered by local authorities who deal with applications and issue badges. The Community Transport Association ([www.ctauk.org](http://www.ctauk.org)) provides the Blue Badge Advice Line.

**British Red Cross**  
44 Moorfields,  
London EC2Y 9AL  
**Tel** 0844 871 11 11  
**Email** information@redcross.org.uk  
[www.redcross.org.uk](http://www.redcross.org.uk)  
Offers a number of services for people with a disability, including a medical equipment loan service and a transport service.

**British Red Cross Scotland, Northern Ireland and the Isle of Man**  
4 Nasmyth Place, Hillington,  
Glasgow G52 4PR  
**Tel** 0141 891 4000  
**Email** scotland@redcross.org.uk  
[www.redcross.org.uk](http://www.redcross.org.uk)  

**Disability Alliance**  
Universal House,  
88–94 Wentworth Street,  
London E1 7SA  
**Tel (voice and minicom)** 020 7247 8776  
**Email** office@disabilityalliance.org  
[www.disabilityalliance.org](http://www.disabilityalliance.org)  
A national registered charity
that works to improve the living standards of disabled people. Provides information on social security benefits and disability rights.

**Disabled Living Foundation (DLF)**
380–384 Harrow Road, London W9 2HU
**Helpline** 0845 130 9177 (Mon–Fri, 10am–4pm)
**Email** helpline@dlf.org.uk
**www.dlf.org.uk**
A national charity that provides free, impartial advice about all types of disability equipment and mobility products through their helpline, website and demonstration centre.

**DIAL UK**
St Catherine’s, Tickhill Road, Balby, Doncaster DN4 8QN
**Tel** 01302 310 123
**Email** informationenquiries@dialuk.org.uk
**www.dialuk.info**
A national network of approximately 120 local Disability Information and Advice Line services (DIALs) run by and for disabled people. Based throughout the UK, the services provide information and advice to disabled people and others on all aspects of living with a disability. You can search for your local DIAL on its website.

**Support for the elderly**

**Age UK**
207–221 Pentonville Road, London N1 9UZ
**Advice Line** 0800 169 6565
**Email** contact@ageuk.org.uk or from the website
**www.ageuk.org.uk**
Age UK, which formed when Age Concern and Help the Aged merged, provides information or advice on anything from health to housing on their free national information line and publishes impartial and informative fact sheets and advice guides.

**National Partners:**
**Age Cymru**
Ty John Pathy, Units 13/14 Neptune Court, Vanguard Way, Cardiff CF24 5PJ
**Tel** 0800 169 6565
**Email** enquiries@agecymru.org.uk
Controlling cancer pain

Age Northern Ireland
3 Lower Crescent,
Belfast BT7 1NR
Tel 0808 808 7575
Email info@ageni.org

Age Scotland
Causewayside House,
160 Causewayside,
Edinburgh EH9 1PR
Tel 0845 125 9732
Email enquiries@ageconcernandhelptheagedscotland.org.uk

Support for children and teenagers

CLIC Sargent: caring for children with cancer
Griffin House,
161 Hammersmith Road,
London W6 8SG
Email info@clicsargent.org.uk
Child Cancer Helpline
0800 197 0068
Email helpline@clicsargent.org.uk
www.clicsargent.org.uk
Provides support to children with cancer and to their families and carers – both during and after treatment, and in hospital and at home.

Teenage Cancer Trust
3rd Floor, 93 Newman Street,
London W1T 3EZ
Tel 020 7612 0370
Email from website
www.teenagecancertrust.org
A charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer and their families and friends, and also raises funds to build dedicated teenage cancer units in hospitals.
Marie Curie Nurses provide free end-of-life care to people with cancer in their own homes 24-hours a day, 365 days a year. There are also Marie Curie hospices across the UK.
Further resources

Related Macmillan information

You may want to order some of the booklets mentioned in this booklet. These include:

- Cancer and complementary therapies
- Controlling the symptoms of cancer
- Coping with fatigue
- The emotional effects of cancer
- Getting travel insurance when you have been affected by cancer
- Help with the cost of cancer

To order, visit be.macmillan.org.uk To order the fact sheets mentioned in this booklet, call 0808 808 00 00.

Audio resources

Our high-quality audio materials, based on our variety of booklets, include information about cancer types, different treatments and about living with cancer.

To order your free CD, visit be.macmillan.org.uk or call 0808 808 00 00.

Macmillan videos

There are many videos on the Macmillan website featuring real-life stories and information from health and social care professionals.

Useful websites

A lot of information about cancer is available on the internet. Some websites are excellent; others have misleading or out-of-date information. The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.
Macmillan Cancer Support  
www.macmillan.org.uk  
Find out more about living with the practical, emotional and financial effects of cancer. Our website contains expert, accurate up-to-date information on cancer and its treatments including:

• our 100+ booklets and 300+ fact sheets

• how Macmillan can help, the services we offer and where to get support

• how to contact our cancer support specialists, including an email form for sending your questions

• local support groups search, links to other cancer organisations and a directory of information materials

• a huge online community of people affected by cancer sharing their experiences, advice and support.

www.cancer.gov  
(National Cancer Institute – National Institute of Health – USA)  
Gives comprehensive information on cancer and treatments.

www.cancer.org  
(American Cancer Society)  
Nationwide community-based voluntary health organisation dedicated to eliminating cancer as a major health problem. It aims to do this through research, education, advocacy and service.

www.cancerhelp.org.uk  
(Cancer Research UK)  
Contains patient information on all types of cancer and has a clinical trials database.

www.healthtalkonline.org
www.youthhealthtalk.org  
(site for young people)  
Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.
www.nhs.uk (NHS Choices)  
NHS Choices is the online ‘front door’ to the NHS. It is the country’s biggest health website and gives all the information you need to make decisions about your health.

www.nhsdirect.nhs.uk (NHS Direct Online)  
NHS health information site for England – covers all aspects of health, illness and treatments.

www.nhsdirect.wales.nhs.uk (NHS Direct Wales)

www.nhs24.com (NHS 24 in Scotland)

www.patient.co.uk (Patient UK)  
Website providing people in the UK with good-quality information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites, some of which are overseas.

www.riprap.org.uk (Riprap)  
Developed especially for teenagers who have a parent with cancer.

www.macmillan.org.uk/Get_Involved/Cancer_Voices/Cancer_Voices.aspx (Macmillan Cancer Voices)  
A UK-wide network that enables people who have or have had cancer, and those close to them such as family, carers and friends, to speak out about their experience of cancer.
Questions you might like to ask your doctor or nurse

You can fill this in before you see the doctor or nurse, and then use it to remind yourself of the questions you want to ask and record the answers you receive.

1. Answer

2. Answer

3. Answer

4. Answer

5. Answer

6. Answer
Notes
Notes
Disclaimer

We make every effort to ensure that the information we provide is accurate but it should not be relied upon to reflect the current state of medical research, which is constantly changing. If you are concerned about your health, you should consult a doctor. Macmillan cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third-party information such as information on websites to which we link. We feature real-life stories in all of our articles. Some photographs are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support’s information development nurses and editorial team. It has been approved by our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

With thanks to: Ms Jackie Chipps, Clinical Nurse Specialist in Palliative Care; Dr Paul Farquhar-Smith, Consultant in Pain Management and Anaesthesia; Dr Joan Hester, Consultant in Pain Management and Anaesthesia; Pauline McCulloch, Palliative Care Clinical Nurse Specialist; and the people affected by cancer who reviewed this edition.

Sources


Can you do something to help?
We hope this booklet has been useful to you. It’s just one of our many publications that are available free to anyone affected by cancer. They’re produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we’re there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

**5 WAYS YOU CAN HELP SOMEONE WITH CANCER**

**Share your cancer experience**
Support people living with cancer by telling your story, online, in the media or face to face.

**Campaign for change**
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

**Help someone in your community**
A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

**Raise money**
Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

**Give money**
Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more
0300 1000 200
macmillan.org.uk/getinvolved
Please fill in your personal details

Mr/Mrs/Miss/Other
Name
Surname
Address
Postcode
Phone
Email

Please accept my gift of £
(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro
Card number

Valid from
Expiry date
Issue no
Security number

Signature
Date / /

Don’t let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you’d rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ
Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That’s who we are.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you’re entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community supporting you online, any time. The fundraisers who make it all possible.

You don’t have to face cancer alone. We can give you the strength to get through it. We are Macmillan Cancer Support.

Questions about living with cancer? Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm) Alternatively, visit macmillan.org.uk


Next planned review 2013. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).